Emotional and social support too rarely provided

Palliative Care Clinic Reaches out to Movement-Disorder Patients

By Tyler Smith

Insights can arrive in unexpected ways. For Benzi Kluger, it was a case of insomnia.

Not his own. The insomniac was a 19-year-old patient afflicted with Huntington disease, a genetic neurologic disorder. She complained of her inability to get to the rest she desperately needed. Kluger, MD, MS, a University of Colorado School of Medicine neurologist specializing in movement disorders and behavioral neurology at University of Colorado Hospital, posed a simple question to her: why can’t you sleep?

I’m afraid of dying, she answered.

It was a watershed moment for Kluger. “I’d been frustrated with my inability to help patients in the typical clinic setting,” he said. “I saw that this patient’s problem was tied to a spiritual issue.”

Much-needed service. The exchange spurred Kluger to create the Supportive and Palliative Care Clinic within the Department of Neurology’s Center for Movement Disorders and Neurorestoration. The center provides treatments, research and education for the entire range of movement disorders, including Huntington and Parkinson’s disease, ataxia, essential tremor, amyotrophic lateral sclerosis, and dystonia.

One of the few palliative care programs in the country specifically designed for neurology patients, it aims to help patients and caregivers address and cope with the emotional ravages of these diseases.

“These are diagnoses that produce sadness and grief,” Kluger said. “Those are reasonable responses to a bad situation. It’s not a psychiatric issue; it’s a psychological and coping issue that challenges people to find meaning in their lives.”

Kluger is medical director for the interdisciplinary clinic (see box), which is currently open one half-day a month in the hospital’s Neurology Clinic with plans to expand to two half-days in May. During a visit, which often lasts two hours, patients and caregivers meet with each team member to deal with the complexities of disease: addressing medical and psychological issues, coping with emotional difficulties, probing spiritual questions, finding medical and financial resources, and so on.

The clinic visits can and do touch on traditional end-of-life topics, such as finding hospice care, completing advance directives, and establishing durable powers of attorney, Kluger said. “There are lots of patients with movement disorders who have not assigned durable powers of attorney,” he said. “As a result, they are dying in hospitals instead of at home.”

Movement disorders specialist Benzi Kluger, MD, directs the Support and Palliative Care Clinic.
Gap in care. Many patients and families affected by movement disorders have significant medical, spiritual, and psychosocial issues, yet they won’t meet the criteria for admission to hospice for years, Kluger added. While these issues often start at the time of diagnosis, Kluger discovered from conversations with Parkinson’s patients that many felt abandoned and lost for several years after learning they had the disease.

“They need good social support and help with psychological issues from the beginning,” Kluger said.

Palliative care for patients with movement disorders is not focused primarily on pain management and symptom control, as it often is with cancer patients, said Wendy Cernik, RN, a neurology nurse who is a member of the Palliative Care Clinic team.

“Cancer patients are often up and about and mobile all the way up to the end of their lives,” Cernik said. “Our patients aren’t. Mobility is their biggest health care issue – and maintaining activities of daily living.”

Cancer patients, Kluger added, generally define their disease in terms of an entity – their tumor – while patients with movement disorders face erosion of their physical and mental abilities.

“The disorders affect who you are as a person,” Kluger said. “That presents particular challenges for caregivers.”

Missing links. A big part of Cernik’s role is to find community resources, particularly home health care, that will help patients with what are routine tasks for many people: getting out of bed, bathing, eating, and cleaning the house. Cari Friedman, LCSW, a social worker with Parkinson’s Association of the Rockies who volunteers with the clinic, also helps link patients and caregivers to community resources.

The job requires sensitivity to the often gray areas of diseases that progress unpredictably. Cernik pulled out a pamphlet loaded with information about advance directives and other health care decisions that lie on the horizon. The first visit is rarely the time to talk about those issues and the medical complexities of life-sustaining tubes and ventilators, Cernik said.

“I suggest that they go home and read the material and think about it, and we can discuss it when they come back,” she said. But they don’t wait too long, Cernik added. “It is good that advance directives and powers of attorney can be discussed earlier in the process rather during the last few days of life.”

Of course, as the young Huntington patient taught Kluger, disease carries a powerful emotional component.

Spiritual search. “At present, Parkinson’s disease and Huntington disease are not curable, but they can be managed,” said Ryan Khan, MDiv, BCC, chaplain with UCH’s Spiritual Care Services Department and a member of the Palliative Care Clinic team. “Palliative care involves issues of spirituality, existentialism, grief, loss and the struggles of patients facing serious chronic diseases and issues of mortality.”

But his clinic discussions with patients and caregivers don’t necessarily center on mortality or death anxiety, Khan emphasized. “The goal is to build relationships with the patient and family in a natural way to determine their values and beliefs and then to help them deal with difficult decisions,” he said.

In broad terms, the Palliative Care Clinic is part of a growing conviction among some in the medical community that treating disease effectively requires more than clinical expertise. A body of research shows that palliative care can reduce hospital costs and improve patients’ quality of life. It can also help to decrease the burden of disease on caregivers, Khan said.

“[The emphasis of the clinic is to] look at patient care holistically and consider how the disease impacts everyone around the patient,” he said. “Medicine is sometimes defined too traditionally as caring for the symptoms of the patient alone. It also imposes physical and mental demands on caregivers.”
Khan probes patients’ and families’ belief systems to help them discover the spiritual wells that can provide them comfort, along with practical stress-reduction techniques, such as meditation, prayer, breathing, support groups – or simply picking up the phone and calling him or another chaplain to talk, an essential outlet for people struggling with many great unknowns.

Cernik began hospice work during nursing school in 1981 and joined UCH three years ago from Denver Hospice. She said she gets many questions from caregivers about the movement disorders their loved ones endure. Psychologist Cynthia McRae, PhD, with the University of Denver, volunteers with the Palliative Care Clinic team, offering additional emotional support.

“Patients and caregivers get a chance to talk about their feelings,” Cernik said, adding that they sometimes do so out of the presence of one another so they can speak more freely.

The success of a palliative care program can’t be judged in purely traditional ways, such as patient volume or cost savings, Kluger concluded.

“The most satisfying thing about the clinic to me is being able to help patients and families make it through a situation which is extraordinarily difficult physically, emotionally and spiritually,” he said. “Sometimes success is helping them die comfortably at home.”

Easing the Burden

The Supportive and Palliative Care Clinic draws on the expertise of an interdisciplinary team that includes hospital and university staff, as well as providers from the community:

- Benzi Kluger, MD, medical director
- Wendy Cernik, RN, neurology nurse
- Ryan Khan, MDiv, BCC, chaplain, Spiritual Care Services
- Cynthia McRea, PhD, psychologist, University of Denver
- Cari Friedman, LCSW, social worker, Parkinson’s Association of the Rockies

Ryan Khan, a chaplain with UCH’s Spiritual Care Services team, helps patients with movement disorders and their families with emotional, spiritual and social support.